



# Analysis of patient participation in the PAUSE to Learn Your Epilepsy self-management education study

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## Overall impact of epilepsy in America

Epilepsy affects over 3.4 million people throughout the United States, with nearly 140,000 people with epilepsy (PWE) residing in Illinois.<sup>1</sup> In 2015, the state of Illinois had the fifth highest number of epilepsy cases in the country.<sup>2</sup> While epilepsy is relatively common, it remains a complex neurologic disorder. About one-third of PWE have uncontrolled epilepsy with life-altering developmental, cognitive, or psychiatric comorbidities. Previous studies have shown an increase in epilepsy self-management (SM) practices leads to improved quality of life and a decrease in depressive symptoms.<sup>3,4</sup> SM for epilepsy includes information and resources PWE can use to develop skills and incorporate behaviors that allow them to control seizures and attain a better quality of life.

## PAUSE to Learn Your Epilepsy Study

PAUSE to Learn Your Epilepsy (PAUSE) is an immersive 8-12-week online SM program that provides PWE an accessible way to learn about their own epilepsy. PAUSE provides epilepsy SM skills to PWE by packaging pre-existing publicly-available information from the epilepsy.com website tailored to each individual's specific needs. This content is delivered through internet-connected tablets, on which PWE can learn and engage at their own pace. PWE from underserved populations face significant barriers to epilepsy management due to a lack of knowledge about epilepsy and epilepsy SM.<sup>5</sup> PAUSE is novel as it aims to reach PWE from underserved areas.

The purpose of this research brief is to identify reasons why PWE who intended to participate in the targeted SM education did not participate and to determine differences between those who participated (P) and those who did not participate (NP). Future research can use these findings to better target PWE in order to reach and retain a diverse population.

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## Methods

Participants of PAUSE were recruited from the University of Illinois Health and Hospital System (UIH) epilepsy subspecialty clinics and through the Epilepsy Foundation of Greater Chicago in Chicago, Illinois. Recruitment and enrollment occurred from October 2015 to March 2019. Eligibility criteria to participate in PAUSE included individuals aged 18 years and older with diagnosed epilepsy, ability to speak and understand English, and absence of any severe or unstable medical co-morbidities that would cause harm or prevent participation. For inclusion in the study, participants, or an adult friend or family member, needed to be able to read at an 8<sup>th</sup> grade reading level, as SM education materials from the Epilepsy Foundation website were written at that level. A detailed study design, including the inclusion and exclusion criteria, as well as a description of the intervention, assessments, and outcomes, are described in an earlier publication.<sup>5</sup> Information about 137 PWE recruited and consented from UIH were analyzed for this report.

Demographics, epilepsy health characteristics, and reasons for nonparticipation were collected through enrollment questionnaires. Gender was categorized as men and women and race/ethnicity was categorized as Hispanic, Non-Hispanic White, Non-Hispanic Black, and Non-Hispanic Other. Education was categorized as having a highschool diploma/GED or less, having at least some college, and unknown/not reported. Insurance type was categorized as uninsured/unknown, Medicaid, Medicare, and private insurance. Averages for age, duration of epilepsy, and seizure frequency were also calculated for participants and nonparticipants.

Reasons for nonparticipation were gathered from nonparticipants and analyzed via withdrawal form or through personal communication with study nonparticipants. Estimates by age, duration of epilepsy, and seizure frequency between participants and nonparticipants were tested using t-tests to determine statistically significant differences. Pearson's chi-squared tests were used to determine significant differences between participants and nonparticipants for gender, race/ethnicity, education, employment, insurance type, and living situation.

# Results

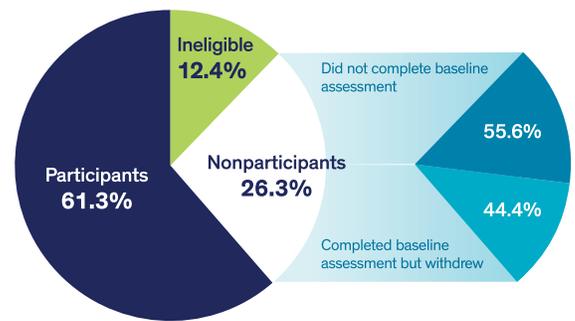
## Overview

- Of the 137 PWE who consented to the PAUSE study from UIH, 17 (12.4%) were ineligible because they did not meet the minimum reading level criteria, 84 (61.3%) participated in the self-management education intervention and 36 (26.3%) did not participate in the study (Figure 1).
- Nonparticipants either did not complete baseline assessment after consenting (55.6%) or completed baseline assessment and withdrew prior to intervention (44.4%, Figure 1).
- PAUSE reached the target population of racially and ethnically diverse individuals in the Chicago area (Figure 2).
- Employment was the only characteristic found to be significantly different at  $p \leq .10$  between those who participated in the study and those who did not (Figure 3). All other differences in characteristics between participants and nonparticipants were not statistically significant.
- One-half (50.0%) of consenting PWE who did not participate were nonresponsive to follow-up phone calls, and over one-third (38.9%) did not participate due to personal/time conflicts (Figure 5).

## Demographic and Contextual Factors

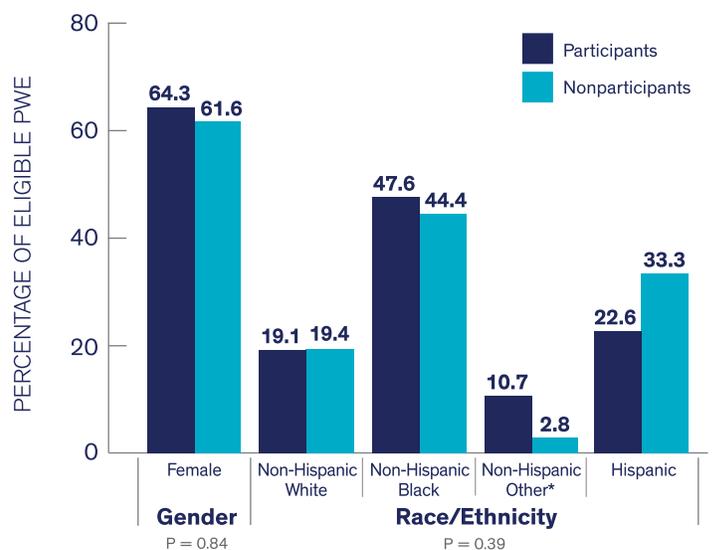
- The PAUSE study reached a diverse population in terms of gender, race/ethnicity, and other demographic factors (Figure 2).
- Age (P: 37.6 years vs. NP: 34.4 years, not shown in figures), gender, and race/ethnicity were not associated with participation (Figure 2).
- About 1.6 times as many participants completed at least some college as compared to nonparticipants (P: 63.1% vs. NP: 38.9%, Figure 3).
- Participants were more often unable to work due to disability (P: 30.5% vs. NP: 19.4%) whereas nonparticipants were more often employed (P: 31.7% vs. NP: 51.6%, Figure 3).
- The majority of both participants and nonparticipants were on Medicaid (P: 63.1% vs. NP: 58.3%). More PWE who participated in the PAUSE study were on private insurance (26.2%) compared to nonparticipants (25.0%). More nonparticipants were on Medicare (8.3%) compared to participants (6.0%, not shown in figures).
- Participants lived alone more often than nonparticipants (P: 15.5% vs. NP: 8.3%, not shown in figures).

FIGURE 1: Percentage of PWE who consented to the PAUSE study by participation



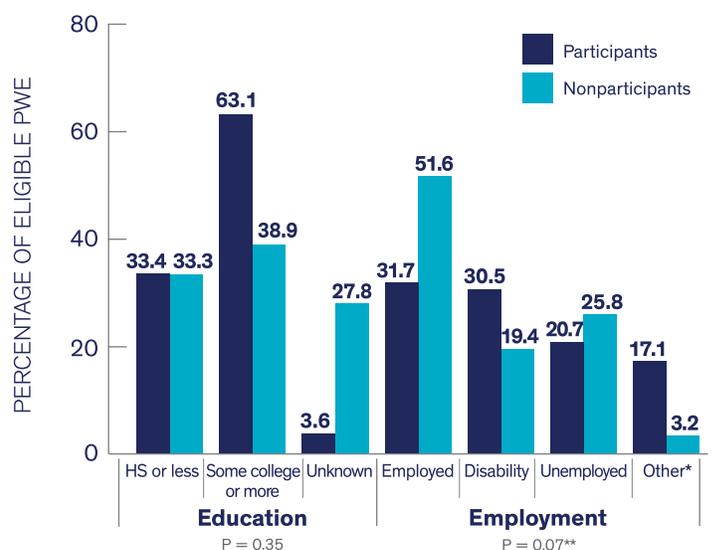
\* PWE = People with epilepsy

FIGURE 2: Percentage of gender and race/ethnicity by PAUSE participation status



\*Non-Hispanic Other = American Indian/Native Alaskan, Asian, and Hawaiian/Pacific Islander

FIGURE 3: Percentage of education and employment by PAUSE participation status



\*Other = Student, homemaker, retired, and volunteer

\*\*statistically significant at  $p \leq .10$

## Epilepsy and Seizure Characteristics

- Participants reported on average 2.0 seizures in the 30 days prior to enrollment and nonparticipants reported 1.6 seizures.
- Participants reported on average 11.7 seizures in the 6 months prior to enrollment and nonparticipants reported 9.2 seizures.
- On average, participants lived with epilepsy for 12.3 years before enrolling (range 0-53) as compared to nonparticipants who lived with epilepsy for 16.0 years (range 0-48, not shown in figures).

## Reasons for Nonparticipation

- Of the 36 nonparticipants, 20 (55.6%) did not complete the baseline assessment and 16 (44.4%) completed baseline assessment but withdrew prior to intervention.
- There were three main reasons why eligible PWE did not participate: (1) nonresponsive to follow-up calls, (2) personal/time conflict, and (3) no longer wished to participate in the study.
- Among those who did not complete the baseline assessment or participate in the intervention, almost one-third did not respond to follow-up calls (30.6%). Nonparticipants also cited personal/time conflicts (22.2%) and no longer wishing to participate in the study (2.8%).
- Among those who completed the baseline assessment but withdrew before the intervention, the most common reason for nonparticipation was a lack of response to follow-up calls (19.4%). Other reasons included personal/time conflicts (16.7%) and no longer wishing to participate (8.3%).

“I don't want to think about or be reminded of seizures. I don't want to have seizures anymore so thinking about them doesn't help.”  
– Nonparticipant

“[I] have a lot going on with school and life, [I] really just don't have the time to do the study.”  
– Nonparticipant

FIGURE 4: Mean seizure frequency prior to enrollment by PAUSE participation status

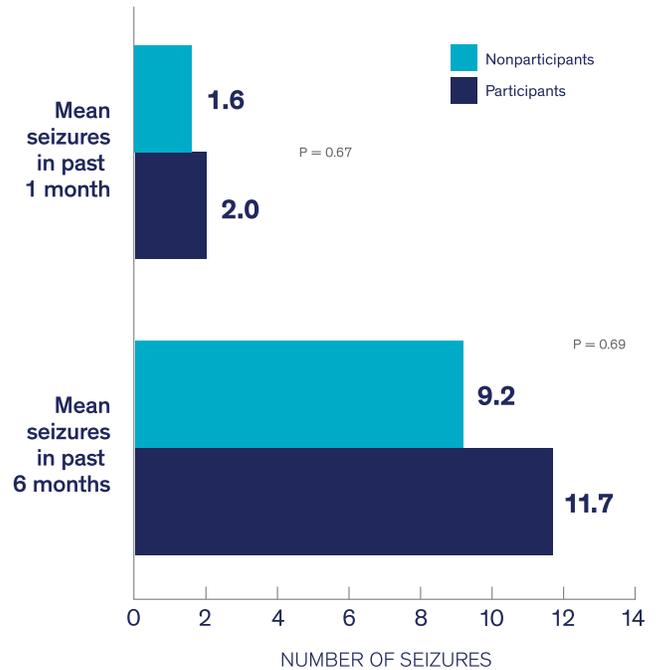
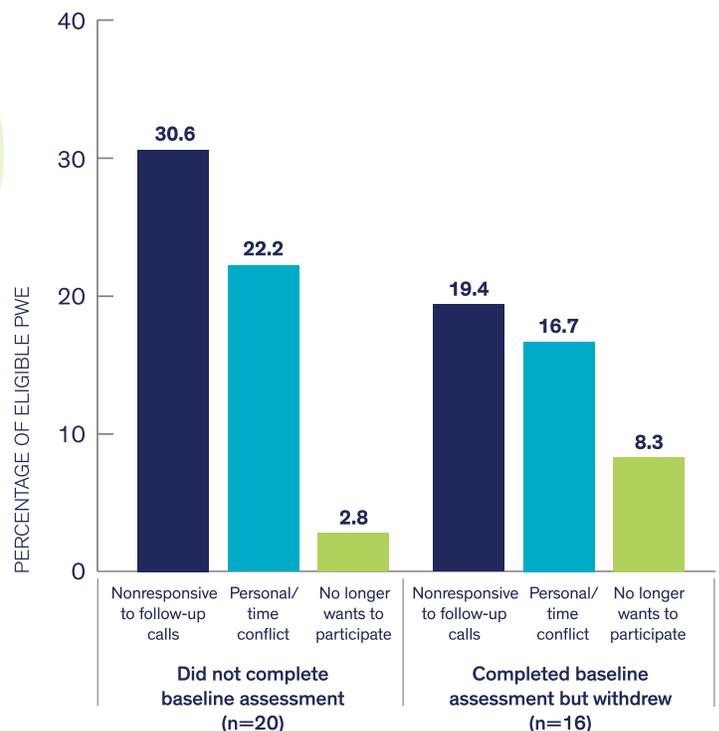


FIGURE 5: Reasons for PAUSE nonparticipation by nonparticipation group



## Discussion

The PAUSE study reached PWE from diverse racial/ethnic backgrounds with varied levels of education and employment status, indicating that the study was inclusive and accessible to the vulnerable populations it sought to reach. However, one-tenth (12.4%) of consenting PWE were ineligible because they (or a friend or family member over age 18) did not meet the reading level criteria. This highlights the fact that the PAUSE study is missing an important underserved population and measures should be taken in order to include those who have lower reading skills. Removing the inclusion requirement for reading level will likely result in a more inclusive group of PWE participants.

While many variables were explored, employment was the only statistically significant characteristic that differed between those who participated and those who did not. PWE who are employed may have less time, be less motivated to participate, or have better seizure control. Results show participants were more often unable to work due to disability whereas nonparticipants were more often employed. More participants were disabled (likely due to their epilepsy diagnosis) and in turn, may have been more motivated to participate in the study.

Several other results support our interpretation that competing priorities discouraged participation in the PAUSE study, while perceived burden of epilepsy increased motivation to participate. Nonparticipants had a longer duration of epilepsy compared to participants. Seizure frequency was higher among participants

compared to nonparticipants. While these comparisons were not statistically significant, they support the idea that participants were more motivated to participate in the study because epilepsy interfered with their life. In contrast, lack of time may be a barrier to participation. We have observed that many patients who did not enroll into the study did not have enough time at the clinic visit to complete the enrollment paperwork due to blood and/or other diagnostic tests on the same day, or transportation conflicts.

Other differences were found between groups, though they were not statistically significant, possibly due to the small study sample size. Education may be a contributing factor to participation, as participants had higher levels of education than nonparticipants, indicating that PWE with higher education may be more interested in SM education.

PWE who live alone may have fewer resources and a weaker support system. Despite this, results show a higher proportion of PAUSE participants lived alone compared to nonparticipants. As those who live alone are among the most socially vulnerable, these findings indicate that PAUSE was able to reach one of the most socially vulnerable PWE subpopulations.

The main reason for nonparticipation among those eligible was nonresponse to follow-up calls (50.0%) followed by personal/time conflict (38.9%). Future studies should be more sensitive to patients' time in clinic and possible transportation barriers by streamlining the enrollment process.

## Definitions

**People with epilepsy (PWE):** People diagnosed and currently living with epilepsy.

**Epilepsy self-management (SM):** Includes information and resources PWE can use to develop skills and incorporate behaviors that allow them to control seizures and attain a better quality of life.

**PAUSE to Learn Your Epilepsy (PAUSE):** PAUSE is an 8-12 week online self-management program that provides PWE an accessible way to learn about their own epilepsy.

**Participants (P):** Recruited patients from the University of Illinois Health and Hospital System epilepsy sub-specialty clinics in Chicago, Illinois that signed consent and continued to intervention.

**Nonparticipants (NP):** Recruited patients from the University of Illinois Health and Hospital System epilepsy sub-specialty clinics in Chicago, Illinois that signed consent but either did not complete baseline assessment or completed baseline assessment but withdrew prior to intervention.

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## SUGGESTED CITATION

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